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Abstract

Inept media trials of clinical trials

The Indian media in general, with the exception of a few domain expert journalists, have failed to comprehend the complexities involved in the clinical trial process. In the run up to the deadline-based coverage of a story, a majority of them fall short in conveying the right perspective to readers, but nevertheless they have been successful in sensationalizing an event in this arena. Possibly by unintended misrepresentation, or mostly out of ignorance of the nuances involved in the clinical trials process, the media has done more harm than good, and got away with it. On the other side, the industry has been reluctant to engage with the media in a meaningful dialog for too long now. It bears not only the consequences of damage to its professional reputation following such reportage, but also the repercussions of unnecessary clampdowns by the regulators. Science journalism in India has yet to rise as a profession.

Key words: Clinical trials, media trials, responsible journalism, stakeholders role

INTRODUCTION

In a lighter vein, the story goes back many years ago when the Pope made his first visit to France. At a press conference that evening, one journalist asked the Pope if he had visited any night clubs. Surprised and taken aback, he enquired if there were night clubs in France too. Next day the following headline got emblazoned on the front pages: *"Pope asks if there are night clubs in France?"* Is this a classic case of a journalist missing the context, or deliberately sensationalizing in reporting for his newspaper?

Coming to science or medical reporting in India, especially in the pharmaceutical and healthcare segments, the journalists assigned to these beats are juniors who are seldom from the science background. The average journalist in this beat can pick up stories related to finance, commerce, regulations, products, services and the like, but can find research-related topics difficult to grasp in the absence of adequate domain knowledge.

Clinical trials are more process-driven operations, subject to strict protocols, and involve many stakeholders. Who does what, at which stage, and why, should be known. Many a time, media only sees the end result of an adverse event, presumes something is fishy, and goes on a story hunt, without confirming the evidence as to the reason of the episode. This arises out of a permanent prejudice borne not only by journalists, but also by the average citizen that, 'people are used as guinea pigs or experimental animals in a clinical trial'.

The same is mostly true of their bureau heads and the editors themselves. The sub-editors, especially in some national dailies, are adept at producing catchy headlines of the stories submitted by the reporters, as if they were competing with the creative directors at the advertising agencies! And to compound matters, most of the media personnel, especially the seniors who are supposed to supervise the reporters, are generally ill aware of the nitty gritty of the reported story. The seniors expect the juniors to learn the subject on the job, which is well nigh impossible in today's racing times of deadlines.

Curious to know the psyche of our junior reporters, I once asked a young lady as to why they blow up negative news. In all earnestness she replied that that's what they were told to do in their journalism class. Little wonder I realized, because many of the senior journalists in Mumbai were the visiting faculty in the south Mumbai College she went to. This must be the case with all journalism schools. The off springs are

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DOI:

10.4103/2229-3485.96442

clones of their masters! I do not for a moment suggest that any bad news affecting society should not be blown up. Although, for heavens' sake, do not blow up the news, the background of which is not clearly comprehended by you. Leave it to the specialists. It does not matter if you did not break the story!

RESPONSIBLE JOURNALISM

When reporting a story, especially in the complex background of clinical trials, the reporter is hard-pressed to fall back on the sources to complete a story. It is here that s/he does not get the required timely support, either from the industry or the medical fraternity. There is indeed a vacuum that leaves the reporters no option but to rely on the oft-repeated phone-a-friend source, who could be biased as well, giving sound bytes unpalatable to the industry. The reporter's strategy is then to get sound bytes on the other side of the story, balance it, and send it to the press. After all, that is what the editor wants, a balanced story!

Unlike the recent dressing down of journalists by the chairman of the Press Council of India (PCI), I believe that the young energetic reporters, despite scripting biased stories, do nevertheless bring out certain facts that all stakeholders need to take cognizance of. It is also the bounden duty of seniors in the media to vet the story and ensure there are no loopholes, before sending it to print. There is a need for responsible journalism, as the story they cover, especially in a discipline that deals with human beings/patients, can have an unintended effect on the society. Let one not forget that clinical trials, conducted in the prescribed manner, are an imperative in the search for better medicine and unmet medical needs of human beings.

The manner in which the media breaks a story, it appears to castigate the very discipline of clinical trials, adding to the abhorrence, fear, and suspicion of all clinical trial activities. Witness the few states in India that recently clamped down clinical trials based on media reports. The media seldom delves deeper into research and investigation, as to what could have gone wrong and why. It is not enough to report the adverse event and leave it at that. If any of the stakeholders, (read industry or Investigators) has deviated from the prescribed process, exposing the exact facts and how it happened is the real story. There is a need for the media to come out with names and what went wrong. It is very nice for a publication to bask in the presumptive glory of breaking a negative story, but if such misrepresentations by a biased media continue frequently, they do not realize the negative consequences of a damaged reputation they are unwittingly wreaking on the industry.

GUINEA PIG MISNOMER

The grasp and significance of science is poorly understood by us as a nation, whether it is atomic power generation or space research, including the highly complex area of drug discovery research. However, the lay public, political bodies, media, and others, do want to have a say whenever they suspect something is wrong, assuming that patients must have been exploited!

This is one suspicion against clinical research that has been existing since the first trials were conducted in the early forties. However, much as science may have advanced, along with global regulations to the fore, this suspicion is difficult to erase. Constant negative publicity to some adverse events that are bound to take place has genuinely created a perpetual monster out of the clinical trials industry. So much so, that the feeling of 'patients being used as guinea pigs' is now permanently set in the psyche of all people in the country.

I shall give just one example of how such things get perpetrated. Very recently, in December 2011, a leading national news channel Editor, otherwise a very good journalist of repute in this country, made an unexpected but out-of-the-habit slip. When reporting on the tragic Kolkata hospital fire and the trauma of common people, in a pontificating announcement he made a reference, "some people carry out experiments on victims of gas tragedy," alluding to the Bhopal gas victims. There was no correlation, but he was wont to say it, to add spice to "the headlines... this evening."

IMPERATIVE TO ERASE NEGATIVE IMAGE

Yes, there were reports earlier of using the gas victims for research. However, let us understand whether it is the Bhopal gas tragedy, a Fukushima-like atomic reactor explosion or any other mass man-made chemical disaster, if people do not get medical help, the political class and the media will be the first to complain of inadequate research by the pharmaceutical industry. It is here that they need to understand that a new molecule has to be tried on a patient suffering from that specific ailment only. The respiratory disorder-related suffering of the Bhopal gas victims is unique and specific and God forbid, even if there is a repeat of such a tragedy in future, a remedy could be on the way, provided the naysayer does not keep harping on using people for experiments.

The industry on its part has done possibly very little to erase the rampant negative image in most people. It has not conceived any process or strategy to allay the fears of the political class, the media, the patients and their relatives, the

NGOs, and so on. True, all law-abiding sponsors follow the set norms of the clinical trial process within the regulatory framework of the country, including the consent process and explaining the patient's rights, and conduct trials by investigators under ethical oversight.

However, that is not enough in a sensitive arena like clinical trials. They have to invest in time and money to communicate not the 'what' and 'how' of clinical trials, but the 'whys' of it. A new drug ultimately needs to be tested on patients for it to be a potentially useful drug. This is why clinical trials on humans is a must and must not be referred to as 'used like guinea pigs,' which does make for a good headline, but not necessarily a responsible one. This is all the more essential in a country like India where the grasp of science and its nuances is regrettably less understood even by the educated class.

STAKEHOLDERS' ROLE

It is here that the industry needs to address the entire media, including seniors, with regular media workshops across the country. It is also pertinent to respond effectively and quickly, explaining the adverse event and pointing out to any possible lacunae in the published news. The very paucity of such timely and appropriate responses from the industry is willy-nilly adding to the poor image of clinical trials.

Second, there appears to be a lack of interaction of the industry with the investigators, especially when it comes to media education and answering media queries. The twain has never met on this front! There is a lot that these two have to do in concert, but appear to remain aloof. Each feels that it is the other's responsibility, when in fact it should have been a joint effort in spreading awareness and allaying unfounded fears.

In a vast country like India, the sheer numbers of illiterate and economically deprived patients can be easy recruitment

targets. The doctors who also double up as investigators, given the time they have, do have a challenging task at hand in protecting the interests of these patients. Then there is the oversight of the 'Ethics Committees,' which still need to fall in place, be regulated in a more transparent manner, and be held accountable for any deviations. An unscrupulous contract research organization (CRO) or industry sponsor can take advantage of the above stakeholders in the absence of a strict and efficient regulatory oversight, which has for various reasons, not kept pace with the pace and stride of the clinical trials in the country. The media should look into these areas while covering a story and expose the black sheep. This can enhance the credibility of the media.

CONCLUSION

One cannot deny that there are unethical practices, but then, by pragmatic assumption, more than 90 to 95 per cent of the trials are process/quality compliant on a sustained basis. That should not deny the truth that the vast majority are well-conducted clinical trials in India, which are indeed required as a way forward for the advancement of human health. Until the country's population as a whole understands that clinical trials on people/patients are a necessary part of the advancement of science and human health, notwithstanding the fact that only a few stakeholders understand this, it will seldom be accepted.

The writer was a former industry researcher who later retired as Editor of Express Pharma Pulse. The opinions expressed herein are personal.

How to cite this article: Ramamurthy NV. Inept media trials of clinical trials. *Perspect Clin Res* 2012;3:47-9.

Source of Support: Nil. **Conflict of Interest:** None declared.